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# The Governor's Advisory Council on Alzheimer's Disease and Related Disorders

## 2000 Annual Report



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Governor

**Jane Swift**  
Lieutenant Governor



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# Governor's Advisory Council on Alzheimer's Disease and Related Disorders

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Dear Chairmen Montigny and Rogers:

I am pleased to present you with the Governor's Advisory Council on Alzheimer's Disease and Related Disorders' Annual Report. The Advisory Council is charged with making recommendations to secretariats, departments, agencies and institutions of the Commonwealth regarding the improvement, coordination, and quality of Alzheimer's care.

The report reviews the history and nature of the disease, provides important information about the caregivers for people with Alzheimer's disease and related disorders in Massachusetts, and details the work of the Council in fiscal year 2000. In addition, the appendices include an overview of the scientific research accomplished in the year 2000.

While the Council spent fiscal year 1999 setting up its organization and priorities, in its second year the Council looked more closely at specific issues of concern to the individuals with ADRD and their families. The Subcommittees explored some of these issues in depth, while the full Council continued to develop relationships with organizations in the Commonwealth that provide services to this population.

I hope that this report helps your continued efforts to make Massachusetts a better place to live with this most devastating disease.

Sincerely,

Lillian Glickman  
Chair, Governor's Advisory Council  
on Alzheimer's Disease and  
Related Disorders



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## **Executive Summary**

The Governor's Advisory Council on Alzheimer's Disease and Related Disorders was convened in September 1998, to provide the Governor, state secretariats, agencies, and the Legislature with recommendations regarding the provision of care to Massachusetts' residents with Alzheimer's Disease or related disorders (ADRD). A particular focus of the Council is the over 610,000 caregivers in the Commonwealth who provide 568 million hours of care annually, an estimated 22.4% of whom care for someone with ADRD.

While the Council spent fiscal year 1999 setting up its organization and priorities, in its second year the Council looked more closely at specific issues of concern to the individuals with ADRD and their families. The Subcommittees explored some of these issues in depth, while the full Council continued to develop relationships with organizations in the Commonwealth that provide services to this population. In December, the Council met with a representative of the Acquired Brain Injury Interagency and Intersecretariat Initiative, which is concerned with developing recommendations to improve and enhance access to comprehensive and coordinated services for people with acquired brain injury (ABI). The Council also met in January with representatives from the federally funded Alzheimer's Disease Centers (ADCs) in the Commonwealth. The ADCs are one part of a program that uses experts at local organizations, which are usually academic centers, to develop infrastructure to draw more people into the study of diseases such as AD.

Family caregivers are the backbone of the long-term care system and the Governor's Council is committed to improving caregivers' services, whether it is through increasing their information about and access to services or providing training and support. Since the Council is required under its legislative mandate to identify sources of funding for service enhancement, and in the interests of addressing these two priorities, the Council submitted an application to the federal Administration on Aging for funding under the Alzheimer's Disease Demonstration Grants to States Program in April 2000. The Council proposed the Minorities with Alzheimer's Services Project, which was designed to ensure that minorities with Alzheimer's disease and their families and caregivers have access to appropriate information and services. While the Council learned in June 2000 that it had not been awarded funding under the ADDGS Program, it will take the MASP proposal, reassess it in light of these comments, and potentially resubmit it in a modified format to other funding sources.

The subcommittees held meetings on a number of issues, including case management, training for nurses and assisted living workers, individuals with a dual diagnosis of AD and mental retardation, elders with dementia living alone in the community, and dementia education in the public school systems.

In fiscal year 2001, the Advisory Council will continue its work through the subcommittees. This will include exploring the issue of people with dementia being transferred back and forth between nursing homes and geriatric psychiatry units in hospitals, developing further relationships with state agencies, and pursuing the issues raised by meetings in fiscal year 2000.



## **Introduction**

In a year in which the airwaves were full of discussion of the future of American public policy, the needs of the aging baby boomer population received a great deal of attention. While discussions of the future of Medicare and Social Security were ubiquitous on the campaign trail, there was less mention of the people who will have to care for the elderly baby boomers in both informal and formal settings. These caregivers, particularly those that care for individuals with Alzheimer's disease and related disorders (ADRD), will face the same challenges that caregivers struggle with today, but there will be many more people stricken with the disease. The Commonwealth's capacity to deal with this situation and the challenges it will pose will be directly affected by its response to ADRD itself.

In fiscal year 2000, the Governor's Advisory Council on Alzheimer's Disease focused on issues that will affect caregivers, both those currently caring for a person with ADRD and those who will be doing so in the future. The Council's efforts were directed in a variety of ways at the need for better education for caregivers, education that can give them to tools to better serve those with dementia, and tools to help with coping with the stresses of caregiving itself. Most of the Council's work looked forward, trying to establish now the mechanisms that will support the caregivers of tomorrow. With its reauthorization in the summer of 2000, the Council's work will continue until at least 2002.

## **Caregivers in the Commonwealth**

### **Alzheimer's Disease and Related Disorders**

Alzheimer's disease (AD) is an irreversible, progressive disease of the brain. AD occurs gradually and results in memory loss, unusual behavior, personality changes, and a decline in thinking abilities. As the disease progresses, individuals' loss of memory results in dementia, which is a loss of the capacity to reason, communicate, and carry out activities of daily life. The disease is the result of the death of brain cells and the breakdown of connections between them. People with AD are not just losing information already learned, but are unable to learn and store new information.

According to the Alzheimer's Association, AD is the fourth leading cause of death among adults after heart attacks, cancer, and strokes. Symptoms of the disease usually begin between the ages of 40 and 90, with the majority of cases in people over the age of 65. The noticeable symptoms span a great period of time, usually four to eight years, but in some cases the illness may last 20 years or more. There is no known cause, although age and family history are identified as risk factors for the disease. The National Institute on Health in its 1998 *Progress Report on Alzheimer's Disease* has described the causation as a "complex cascade of events that takes place inside the brain...[T]here is no single cause of AD, but the disease can be triggered by any number of small changes in this cascade...."<sup>1</sup>

There is a great deal of research being conducted to determine what role genetics may play in the onset of the disease, create new and more accurate diagnostic tools, develop new medications, and, perhaps most excitingly, develop a vaccine against Alzheimer's disease. For a complete

discussion of the advances made in Alzheimer's research in calendar year 2000, see Appendix A, which contains a report generated by the national Alzheimer's Association.

It is important to note that dementia is not a natural part of the aging process. Unfortunately, there is still considerable public misconception about this fact. As the federal Institute on Aging and the National Institutes on Health have said, "Although the risk of developing AD increases with age, AD and dementia symptoms are not a part of normal aging. AD and other dementing disorders are caused by diseases that affect the brain. In the absence of disease, the human brain often can function well into the tenth decade of life."<sup>2</sup>

While Alzheimer's disease is the most common form of dementia, representing 56% of cases, it is not the only one. Many other conditions and disease also cause the confusion and behaviors that can be mistaken for AD. These related disorders include Creutzfeldt-Jakob disease, multi-infarct dementia, Pick's disease, Parkinson's disease, Lewy Body disease, and conditions like depression, drug interaction, and thyroid problems.<sup>3</sup> In light of these many similar conditions, all of which have different treatments and some of which can be cured, accurate diagnosis is crucial.

Due to the lack of a registry of diagnoses and the number of individuals with dementia who have not been formally diagnosed, there is no official number of people with ADRD in the Commonwealth. Therefore, the Alzheimer's Association and the Executive Office of Elder Affairs generated prevalence estimates for each town in the Commonwealth in April of 1999.\* According to one of the most frequently cited studies of prevalence rates, which assessed more than 3,600 people living in Boston, 10.3% of those age 65 and older have ADRD.<sup>4</sup> The highest rate in the study, 47.2%, occurred in those over age 85. Using 1995 census estimates, therefore, there were approximately 130,000 people with ADRD in Massachusetts in 1995. As the population ages, the number of people with ADRD will grow, too. As the population over the age of 85 is the fastest growing segment of the elder population and is projected to increase 81.9% between 1990 and 2010, the incidence of ADRD can be expected to increase dramatically.<sup>5</sup>

## **Informal Caregivers for Individuals with ADRD**

While ADRD is devastating for the person with dementia, family caregivers carry a tremendous burden. According to Jeannette Takamura, Assistant Secretary of the Administration on Aging, "Informal caregiving by family and friends is the backbone of America's long-term care system."<sup>6</sup> While the popular conception of aging may be elderly people living in nursing facilities, about 70% of people with AD live at home, and family and friends provide almost 75% of their care. In fact, of all community-dwelling elders with chronic disabilities, almost 50% only receive unpaid, informal care.<sup>7</sup>

Family caregivers assume many costs that the Commonwealth would otherwise provide in caring for individuals with ADRD, greatly reducing reliance upon publicly funded services. There are over 610,000 caregivers in the Commonwealth who provide 568 million hours of care annually,

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\* For the town-by-town breakdown of the prevalence of ADRD, visit the Alzheimer's Association web page at [www.alzmass.org/prevalence.htm](http://www.alzmass.org/prevalence.htm). The Council will regenerate these estimates when the Census 2000 numbers become available.

at a value of \$4.646 billion.<sup>8</sup> It is estimated that 22.4% of these caregivers care for someone with AD.<sup>9</sup>

In a study of whether psychosocial interventions\* for caregivers prevented nursing facility placement of individuals with ADRD, researchers found that supporting caregivers delayed placement by almost a year.<sup>10</sup> This delay could be significant to the Commonwealth, given that the average cost of a publicly funded nursing facility bed is about \$120 per day, or as much as \$45,000 per year, and that 75% of the 56,248 nursing facility residents in the state are MassHealth clients.<sup>11</sup> Recognizing that individuals in the community are often receiving some formal services in addition to their family's care, achieving even a six-month delay in placement for the 130,000 individuals with ADRD in Massachusetts could save the Commonwealth millions of dollars. Sufficient support and training for family members would therefore not only sustain the informal caregiving system, but could make economic sense.

And caregivers do need that support. Caring for a person with ADRD places great demands upon family members. Alzheimer's caregivers provide, on average, 49% more hours of care per week than non-Alzheimer's caregivers (17.6 vs. 11.8 hours per week). In addition, Alzheimer's caregivers are twice as likely to be providing care more than 40 hours per week.<sup>12</sup> Alzheimer's caregivers are more likely to be taking care of a relative than non-Alzheimer's caregivers (89% vs. 84%), are somewhat older (46% over the age of 50, vs. 36%), and more likely to be female (76% vs. 71%).<sup>13</sup>

The nature of the disease, as well as additional burdens of Alzheimer's caregivers reflected in the numbers above, contribute to the strain and stress that the majority of caregivers feel. A Kaiser Family Foundation survey of people caring for a parent age 65+ found that 53% feel worried and 37% feel frustrated. The survey showed that, in particular, women caregivers are concerned about juggling caregiving with other responsibilities (44%), having enough time for themselves (33%), and having enough time for a spouse or partner (29%).<sup>14</sup> Of course, this survey was not focused solely on Alzheimer's caregivers, who are older and often providing more intense care.

While all caregiving can be challenging, researchers have found that caring for someone with dementia is "more stressful than caring for someone with a physical disability.... Toward the end, communication is problematic and the reciprocity that happens in a relationship wanes.... With a physical disability, you can still be a partner on an emotional level."<sup>15</sup> Compared to caregivers for people with Parkinson's disease with no dementia, for instance, Alzheimer's caregivers were "more depressed, more anxious, and had lower psychological well-being."<sup>16</sup> Approximately 50% of those caring for people with severe Alzheimer's report suffering from clinical depression, and about a third die before the individual for whom they are caring.<sup>17</sup>

It is important to note, however, that caregivers also report on the benefits of caregiving. The Kaiser survey found that 96% of caregivers in this survey felt loving, 90% felt appreciated, 84% felt proud, and 78% felt hopeful.<sup>18</sup> Another study found that caregivers find there are positive changes to their concept of themselves,<sup>19</sup> presumably because of the altruistic nature of their activities.

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\* Psychosocial interventions include support groups, on-going counseling and care planning, and training in behavioral management.

As well as taking a toll on caregivers' emotions and time, there is a significant financial toll. On average, caregivers nationally pay \$19,525 out-of-pocket in order to help the care recipient. The three most common expenses are food, transportation, and medication, but housing costs and formal care were the most expensive items.<sup>20</sup> The amount of money coming into the household is also often affected; family caregivers' work performance suffers as a result of their responsibilities. Nationally, about 64% of all caregivers are working full or part-time and 41% are also taking care of children under the age of 18.<sup>21</sup> As a result of their dual responsibilities, 84% of caregivers report making informal changes to their work schedule, such as arriving late or making personal phone calls, and 64% report making formal changes to their schedule, including using sick or vacation time and decreasing the number of hours worked. These changes result in an average loss in wage wealth for caregivers of \$566,443.<sup>22</sup>

Finally, there is an enormous cost to American businesses. A national study conducted by the Alzheimer's Association estimated that the cost to US businesses is approximately \$33.2 billion per year. This figure includes absenteeism, productivity loss, replacement of workers and other caregiver costs, as well as over \$7 billion in ADRD related health care costs and taxes paid by businesses that are used for AD research.<sup>23</sup>

In the future, caregiving is going to gain greater attention than it does currently; perhaps the recently passed National Family Caregiver Support Program is the beginning of this trend. Two demographic trends, the increase in life expectancy and the decrease in the number of children of the baby boomer generation, are contributing to the already well-publicized increase in the elder population.<sup>24</sup> These factors, combined with the increase in workforce participation among women, the increased average age of childbearing, the geographic dispersion of American families, and the increase in the rate of divorce, contribute to a decline in the amount of caregiving provided by family members. Currently, there are 4.6 working adults for each elder in Massachusetts. In 2025, that ratio will be 3.3 workers for each elder.<sup>25</sup> As well as affecting the number of available caregivers, this demographic trend will mean a decline in the number of taxpayers paying into the public programs that pay for the formal caregiving system, which includes Medicaid, state funded programs, and Medicare.

## **Formal Caregivers for Individuals with ADRD**

While informal caregivers are critical to the care of people with ADRD, there is a great deal of care paid for by the Commonwealth, which is provided by professional or formal caregivers. Services are provided in a variety of community and residential settings, including individual's homes, dementia day care centers, and, increasingly, Councils on Aging. Recognition is growing that dementia affects an increasing number of elders in the community and that service providers in the community need more training in behavioral management techniques in order to better serve individuals with dementia.

The costs to the Commonwealth come in the form of Medicaid payments to nursing homes and adult day health programs, services provided by the Aging Services Access Points (ASAPs) through the Home Care and Respite Care Programs, as well as other, less quantifiable costs. While there are no other reliable numbers available on long-term care expenditures for people with ADRD in Massachusetts, approximately 50% of those in nursing facilities are thought to

have dementia. Given that prevalence, of the approximately \$1.2 billion spent in the Medicaid program on 33,770 Medicaid recipients in nursing homes, approximately \$600 million would be spent on individuals with ADRD.

Of all community services, respite care may be one of the most valuable and underutilized interventions available. “Respite, or time away from the responsibilities of care, is essential if caregivers are to protect themselves from depression and other health problems while continuing to provide care at home for as long as is feasible.”<sup>26</sup> Respite services have been shown to reduce caregiver burden and also to reduce caregiver depression.<sup>27</sup> And as mentioned above, psychosocial interventions targeting family caregivers in the home were found to have the greatest impact on how long people with dementia stay alive, functional and living at home.<sup>28</sup> Recognizing this, Massachusetts created the Respite Care Program in 1984, which traditionally has included homemaker, personal care, home health services, adult day services, dementia day services, laundry services, home delivered meals, personal emergency response, transportation, adaptive housing, grocery shopping, chore and short term residential care.

The Executive Office of Elder Affairs, through its contracts with the ASAPs, spent \$4.8 million on the Respite Care Program, which included \$362,577 for dementia day care. Elder Affairs also spent an additional \$624,403 on dementia day care through its four other home care programs. All of Elder Affairs’ home care programs served 1602 clients with a diagnosis of Alzheimer’s in fiscal year 2000, which represents 4% of the total Home Care Program caseload. Given the expected prevalence rate for ADRD in the over age 65 population, that low number may reflect a lack of formal diagnosis of the disease. The most likely reasons for the low level of services are 1) at-risk elders do not report their medical or other problems, and 2) public resources to locate high-risk elderly or to serve people with ADRD and their caregivers are uniformly lacking.<sup>29</sup> It is also possible that clients and their family caregivers do not report a dementia diagnosis to the ASAP unless necessary; ADRD still carries a significant stigma in the community.

## **Council Activity in Fiscal Year 2000**

### **Brief History of the Council**

The Governor’s Advisory Council on Alzheimer’s Disease and Related Disorders was convened in September 1998. It was first authorized in Chapter 204 of the Acts of 1996, and then reauthorized in Section 379 of Chapter 194 of the Acts of 1998. The Council is charged by the legislation with the following goals:

- To recommend the delivery of services in the most effective and efficient manner possible, including identifying means of coordination and cooperation among different state agencies and departments in order to achieve cost savings and to facilitate meeting the needs of people with dementia or their caregivers;
- To identify additional sources of federal and private sector funding with which the Commonwealth may provide additional services and programs for people with dementia and their caregivers;
- To promote public and professional awareness and education relative to dementia and access to dementia services and programs;
- To identify service delivery mechanisms that enhance the quality of life for people with dementia and their caregivers; and

- To evaluate and coordinate implementation of recommendations made in 1994 by the Governor's Conference on Alzheimer's Disease.

Members of the Council, according to the legislation, are to be appointed by the Governor, the President of the Senate, and the Speaker of the House. There are seventeen appointed members. They are:

*Chair:* Lillian Glickman, Secretary of the Executive Office of Elder Affairs  
Sandra Albright, Executive Director, Kit Clark Senior Services, Dorchester;  
Judith Antonangeli, Director of Alzheimer's Project, Cooperative for Human Services, Inc.,  
Malden;  
Vincent Ciampa, State Representative, Somerville;  
Carol Cleven, State Representative, Chelmsford;  
Dr. Joan Garity, Ed.D., RN, Associate Professor, UMass Boston, Boston;  
Barbara Gloss, Elder Affairs' Citizens' Advisory Council, Winthrop;  
Kathryn Hedgepeth, Regional Director, Alzheimer's Association, Massachusetts Chapter,  
Easthampton;  
Joanne Koenig-Coste, M.Ed., President, Alzheimer's Consulting Associates,  
Framingham;  
Ruth Moy, Executive Director, Greater Boston Chinese Golden Age Center, Boston;  
Douglas Petersen, State Representative, Marblehead;  
Paul Raia, PhD., Director of Patient Care and Family Support, Alzheimer's Association,  
Massachusetts Chapter, Cambridge;  
Diane Sibley, Community Advocate, Boston;  
Ralph Stefanelli, Community Advocate, Norton;  
Virginia Tierney, Elder Affairs' Citizens' Advisory Council, Quincy;  
Marian Walsh, State Senator, Boston; and  
Kathleen Walsh, Department of Public Health.

Other people who have attended meetings are Ann Hartstein, Ellen Birchander, and Eliza Lake of the Executive Office of Elder Affairs; Patricia Baumer of Representative Vincent Ciampa's office; Elena Choy, a family caregiver; Deborah Thomson, Susan Kelly-Grasso, and James Wessler of the Alzheimer's Association, Massachusetts Chapter; Cathy Pastva of the Alzheimer's Association of the Cape and Islands; Ann Hurley of the Boston University Alzheimer's Center; Roberta Rosenberg of the Multicultural Coalition on Aging; Daniel O'Leary of Mystic Valley Elder Services; and Linda Connor-Lacke, a community member.

In addition to covering the information provided below, every meeting of the Council served as a roundtable discussion of the most recent information in the field of Alzheimer's care. Information shared included updates about educational opportunities, the latest research findings, regional events, agency activities, policy changes, and upcoming conferences. In this way, the Council has served as a statewide forum for the dissemination of information and as a brainstorming arena, a function that will contribute to achieving the goal of improving services to people with ADRD across the state.

## Council Activities in Fiscal Year 2000

In fiscal year 2000, the subcommittees carried out the majority of the Council's work. The full Council met five times in meetings that covered the following topics:

### September 22, 1999

The Council reviewed the Fiscal Year 1999 Annual Report and discussed its distribution. It also discussed the Council's goals for the upcoming year, and decided that the goals laid out in the previous year should continue to be pursued. The Subcommittees gave extensive reports about their activities (see Subcommittee Activities, below).

### December 2, 1999

In addition to Subcommittee reports and an overview of the state budget, there was a presentation by Francesca LaVecchia, Chief Neuropsychologist of the State Head Injury Program (SHIP). Dr. LaVecchia spoke to the Council about the Acquired Brain Injury Interagency and Intersecretariat Initiative. This group was convened in 1997 to identify the acquired brain injury (ABI) population, and the state agencies that serve it, and to address the fragmented nature of the ABI services delivery system. Please see Appendix B for a fact sheet about the Initiative.

Dr. LaVecchia then presented an overview of what is defined as ABI, including its epidemiology. There are many causes or types of ABI, including vascular disorders, traumatic brain injury, metabolic disorders, infectious disorders, neurotoxic disorders, and neuromuscular disorders. Neoplastic disorders, which include tumors in the brain, increase after the age of 50 and again after the age of 70. This second jump in the incidence is because 50% to 75% of brain tumors are the result of metastases from another, earlier cancer. This means that many of the elders who may be diagnosed with another disease (including a dementia) may in fact be suffering from a brain tumor, which points out the increased importance of taking a very comprehensive history in any intake process.

Finally, there are degenerative dementing disorders, like Alzheimer's disease, Pick's disease, and multi-infarct dementia. The latter occurs not when a person has one stroke, but when his/her brain is assaulted by multiple, small strokes. Other types of degenerative dementia are caused by AIDS, which is called AIDS Dementia Complex (ADC), alcoholic dementia, and dementia caused by multiple traumatic head injuries.

### January 26, 2000

Secretary Glickman announced that the U.S. Administration on Aging would release a Request for Proposals in March for its Alzheimer's Disease Demonstration Grants to States (ADDGS) program. The ADDGS program has provided funding in the past to state agencies, working in collaboration with Alzheimer's Associations and other private community groups, to provide increased respite services, outreach, and training on dementia issues. As the Council is charged in its legislative mandate with identifying other sources of funding for Alzheimer's programming, a grant committee was formed to address this opportunity. See the discussion below of the subcommittees' activities for more information about the ADDGS proposal that was submitted in April 2000.

The two federally funded Alzheimer's Disease Centers (ADCs) gave presentations to the Council about their activities. Dr. Ann Hurley, Director of the BU AD Center's Information Transfer Core, explained that the National Institutes of Health created the ADCs in the 1970's. They are part of a larger program that uses experts at local organizations, which are usually academic centers, to develop infrastructure to draw more people into the study of a number of diseases. There are a number of core components of the ADC, which work on separate aspects of the Center's work: the Administration, Clinical, Neuropathological, Education and Information Transfer, and Animal Cores. Other Core activities have included providing grant-writing workshops, and contributing or producing a number of publications.

Roberta Rosenberg, Project Director of Massachusetts General Hospital's Alzheimer's Disease Center's Information & Dissemination Core, reported they are engaged in similar work. The Core's goals are to provide professional education, disseminate information to minority communities about ADRD, and to increase knowledge about the similarities and differences between normal aging and ADRD. Toward this end, the Core has partnered with Beth Israel Deaconess Medical Center and Harvard Medical School to rotate medical residents through the Memory Disorders Clinic at the Hebrew Rehabilitation Center for the Aged. Ms. Rosenberg also serves as the Chair of the Multicultural Coalition on Aging, which comprises 56 agencies from the Boston area. The ADC funds the Coalition. Finally, the Information and Dissemination Core has a Memory and Aging Project, which involves examining the cognitive changes and neuropathological differences between a normal aged brain and one with Alzheimer's disease.\*

### **March 23, 2000**

After Subcommittee reports, the meeting was devoted to a discussion of the ADDGS grant application. The Administration on Aging (AoA) released a request for applications for funds from the program, which is currently providing funding to fifteen states. It was clear, in looking at the requirements of the program, that the Council had already developed recommendations that could be used to create a proposal

A draft proposal, developed by Elder Affairs and the Alzheimer's Association, would create partnerships both at the state and local level, between state agencies and community providers. It would target communities with a large minority population, and would create dementia specialists in the ASAP most appropriate for the community. See the discussion below for a longer description of the preliminary and final application proposals.

### **May 24, 2000**

This meeting of the Council was devoted to a number of separate issues, including:

- Distribution of a final copy of the ADDGS application, which had been submitted April 21, 2000 to AoA;
- Discussion of the fiscal year 2000 annual report's format and distribution;

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\* For more information on the Alzheimer's Disease Centers, visit their web sites: <http://www.xfaux.com/alzheimer/> (Boston University) and <http://neuro-oas.mgh.harvard.edu/alzheimers/> (Massachusetts General) or visit the National Institute on Aging website on all the ADCs at <http://www.alzheimers.org/pubs/adcdir.html#mas>

- Inclusion of registration in the Safe Return program to the purchased services that ASAPs can offer to their home care clients, an issue in which the Council has expressed interest;
- Overview of the Senate and House budgets for fiscal year 2001, which both contain reauthorization language for the Council;
- A report released by the National Conference of State Legislatures titled *Alzheimer's Disease and Related Dementias: A Legislative Guide*\* and approval of a letter sent to legislators pointing out the similarities between the recommendations made in the *Guide* and the Council's recommendations; and
- Governor Cellucci signed Executive Order #421 on May 10<sup>th</sup> at his Conference on Aging, which will be a chance for a comprehensive assessment of the gaps in the long-term care systems and the development of new models of care.

## Subcommittee Activities

Each subcommittee held a number of meetings in fiscal year 2000, the topics of which occasionally overlapped with other subcommittees' activities. As a result, the following discussion is organized according to topic areas, rather than by subcommittee. The topic areas include support for informal caregivers through case management and the Alzheimer's Disease Demonstration Grants to States Program, training for formal caregivers such as nurses, nursing facility staff, and assisted living staff, and education for children and teachers in the Commonwealth's schools.

### Informal Caregivers – Case Management

On August 31, 1999, the Coordination and Enhancement of Services Subcommittee explored the issue of case management for individuals with ADRD and their families. The group was interested in learning more about the weaknesses in the current system, and exploring ways in which to improve upon or change it to better serve the needs of this population.

The Subcommittee discussed a possible model of enhanced case management for people with ADRD, where a person in the community is designated as the coordinator of services for an individual. This person would keep track of the client's daily or weekly status, and keep the caseworker at the responsible ASAP apprised of his/her changing needs. The group recognized the need to not develop an entirely new program but to build off of existing resources. Another important issue raised was access to services for all the individuals and families who are not currently in the system. While improving case management will help those people who are already in touch with the elder network, there needs to be continuing emphasis placed on getting information out to the public about the services available.

The Subcommittee met on September 22, 1999 with representatives from the Executive Office of Elder Affairs and a number of Aging Services Access Points (ASAPs) about the Chronic Care Initiative. The Chronic Care Initiative is a pilot project, funded by Elder Affairs, in which a

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\* For a copy of the *Guide* (ISBN 158024081X, \$20), call the National Conference of State Legislatures publication department at (303) 830-2054, send a fax to (303) 863-8003 or e-mail your order to books@ncsl.org.

number of ASAPs are developing programs to provide enhanced services to elders with certain chronic conditions, including dementia.

These discussions served as the basis for the proposal submitted to the AoA for funding under the ADDGS program, discussed below. The focus on involving family and/or community members in the care planning process, the outreach to all community members, and an interagency public education campaign were the result of the Subcommittees' conversations.

### **Informal Caregivers – The ADDGS Proposal**

As the discussion at the beginning of this report makes clear, the support of informal caregivers is critical to the provision of adequate services for individuals with ADRD. The Governor's Council is committed to improving caregivers' supports, be they in the form of increased access to dementia day care, increased respite care, or training and education. In addition, the Council is required under its legislative mandate to identify sources of funding in order to enhance the services available to individuals with ADRD and their families.

In the interests of addressing these two priorities, the Council submitted an application to the federal Administration on Aging (AoA) for funding under the Alzheimer's Disease Demonstration Grants to States Program (ADDGS) in April 2000. AoA required that proposed programs address two priority program objectives: 1) develop models of assistance for persons with Alzheimer's disease and their families; 2) improve the responsiveness of the existing home and community based care systems for persons with Alzheimer's disease and related disorders and their families.

The Governor's Advisory Council, through the Massachusetts Executive Office of Elder Affairs' application to ADDGS, proposed the Minorities with Alzheimer's Services Project (MASP). The MASP proposal was designed to ensure that minorities with Alzheimer's disease and their families and caregivers have access to appropriate information and services. MASP would have created a link between the Alzheimer's Association and two Aging Services Access Points (ASAPs) that currently provide the majority of home care services to frail, low-income elders in their communities. The application requested \$350,000 a year for three years from AoA.

MASP would have provided services through a combination of outreach and care planning. Outreach Workers would have identified minorities with Alzheimer's disease and their families in two designated ASAP service areas and provided them with support and education about dementia. At the same time, the Workers would have referred the families to the designated ASAPs. A Dementia Specialist at the ASAP would have worked with case managers to create a care plan for identified families that was appropriate in terms of both cultural competency and the clients' diagnoses. Care plans would have included the provision of direct services such as home health and homemaker services, dementia day care, and companion services.

MASP would have provided a number of crucial enhancements to the provision of services in the Commonwealth to individuals with ADRD and their families. More specifically, these included:

- An enhancement of the Respite Program's services by adding a home assessment that includes a dementia-specific care plan, training for family members/caregivers, and a home modification plan;

- Creation of a formal process to provide training and resources for ASAP workers regarding appropriate outreach and services to minorities with dementia and their families, including on-going in-house support;
- Development of a partnership between Elder Affairs, the Department of Public Health (DPH), the Governor's Advisory Council on Alzheimer's Disease, the Massachusetts Chapter of the Alzheimer's Association, and the federally funded Alzheimer's Disease Research Centers; and
- Launching a public education campaign that would have included outreach to primary care physicians, community health centers, and community organizations such as Councils on Aging and senior centers.

In June 2000 the Council learned that it had not been awarded funding under the ADDGS Program. The Council will take the MASP proposal, reassess it in light of comments received from the AoA review committee, and potentially resubmit it in a modified format to other funding sources.

### **Formal Caregivers – Nurse Education**

The Professional Education Subcommittee's objective is to ensure that health care professionals across the spectrum understand the medical, social, and functional needs of dementia patients and their families, and that they have knowledge of those services available to this population. In fiscal year 2000, the Subcommittee targeted nurses, including LPNs, RNs and those with post-graduate degrees, as critical providers of services to individuals with ADRD and their families. The subcommittee held meetings with a number of nurse organizations in an effort to better understand the current state of dementia education for nurses.

On November 16, 1999, the Subcommittee met with representatives from the Massachusetts Nurses Association (MNA). The group discussed what requirements and opportunities currently exist in nursing continuing education. Suggestions were made about ways of reaching this group with educational materials. In order to learn more about the initial education of nurses in the Commonwealth, the Subcommittee first met with a representative of the Massachusetts/Rhode Island League of Nursing on March 3, 2000, and then with a number of other nurse organizations on June 19, 2000. These organizations included representatives from the Massachusetts Association of the Colleges of Nursing, the Board of Registration in Nursing (BORN), and the Center for Healthcare Professions at Worcester State College.

The discussions at these meetings covered a wide range of topics, including the fact that nurses provide the majority of formal dementia care, many nurses will be retiring in the next 25 years since the average age for a nurse in Massachusetts is currently 44 years old, graduating nurses largely go into acute care settings, and there appears to be little interest in geriatrics. While there is currently no data about what populations most nurses are working with or what their specialization might be, there are a number of efforts underway to elicit this information. Most notably, the Center for Healthcare Professions is sending a survey to 73,000 nurses in the Commonwealth to determine their activities since they took the Board exams.

The group agreed that as a first step the Subcommittee, in consultation with the BORN, would develop a survey to be sent to all the nursing schools in the Commonwealth. The survey would

elicit information about their curricula and how it covered dementia and, more generally, geriatrics. It would also include a question about whether there is a need for a nursing specialization in geriatrics or nursing. As BORN conducted a similar study of basic nursing education programs in 1992, the Subcommittee developed the survey based upon the instrument used at that time. A copy of the survey is attached in Appendix C. Results are expected to be available in 2001.

### **Formal Caregivers – Assisted Living Workers’ Training Requirements**

As was reported in the fiscal year 1999 Annual Report for the Council, the Coordination and Enhancement Subcommittee made preliminary recommendations about training requirements for people working in assisted living facilities. These recommendations were a further topic of discussion in fiscal year 2000. The Council met with the Massachusetts Assisted Living Facilities Association (MASS-ALFA) and the Alzheimer’s Association on November 18, 1999 to discuss the need for training for assisted living facility staff, and the best way to provide that training. As a result of the meeting, the Subcommittee modified its previous recommendation regarding training requirements to the following:

- Require that the initial orientation in which all staff participate be expanded from six hours to eight, with two hours devoted to dementia issues;
- Require that those staff members who provide personal services to residents receive eleven hours of in-service training annually, five hours of which must be devoted to dementia issues, an increase from the current requirement of six hours;
- Require all managers and supervisors receive an additional two hours of training on dementia issues annually; and
- Require that behavioral management issues be addressed in residents’ care plans, as medication management is now. This would require supervisors and individual workers to discuss each individual resident’s behaviors, and would enable the Executive Office of Elder Affairs, as the certifying state agency, to track whether residents’ behaviors are being addressed appropriately. This would also allow for some outcome measurement.

### **Public Education – Schools**

The Public Education Subcommittee met with the Massachusetts Department of Education (DOE) on September 16, 1999 to discuss the incorporation of information about Alzheimer’s disease and related disorders into the curricula of primary and secondary schools in the Commonwealth. DOE cannot and does not mandate the content of health education in schools. Instead, it provides funding each year to school systems to provide health education in myriad settings. Guidance for this health education system comes from local Health Advisory Councils, which are groups of community and school members who are charged with developing curricula, training staff, and working with the health coordinator in each school.

The Health Advisory Councils are provided with a Health Curriculum Framework by DOE, which outlines suggested principles and learning standards for each grade and subject. Some of these guidelines lend themselves naturally to instruction about dementia and the people who are affected by it.

## Other Subcommittee Activities

Besides the issues discussed above, the Subcommittees held meetings on a number of other subjects. They included a meeting on March 23, 2000 between the Coordination and Enhancement of Services Subcommittee and representatives from a program in the Metro Region office of the Department of Mental Retardation that provides outreach and education to families with an individual with Down Syndrome. This program was developed in response to the fact that all people with Down Syndrome develop the neuropathology of Alzheimer's disease. The Subcommittee agreed that it should explore such a program being replicated in other DMR regions in the Commonwealth.

On January 11, 2000 the Coordination and Enhancement of Services Subcommittee met with a representative from the Elder At Risk Program (EAR) and a representative of the Massachusetts Association of Resident Service Coordinators in Housing to discuss the issue of elders living alone in the community who may have dementia. The EAR program, primarily administered by the ASAPs, serves people who are 60 years of age or older who are unable to meet their own essential needs (food, clothing, shelter, etc) due to cognitive, physical, or other impairment.

The EAR program, since it is focused on elders who live alone, frequently deals with difficult cases in which the elder is isolated and very resistant to receiving services. This problem is even greater when the client has AD, particularly in the later stages. While the EAR program is dedicated to keeping elders in their homes and as independent as possible, these cases often require the assignment of a guardian and/or placement in an AD-specific residential facility.

The representative from the Massachusetts Association of Resident Service Coordinators in Housing (MARSCH) explained that, in general, the majority of referrals to the service coordinator in an elderly housing project are informal; a resident is brought to his/her attention by another resident, a maintenance worker, or someone else who is concerned about the health and safety of the resident. The service coordinator will then meet with the elder, offer him/her some information, and work with the local ASAP to make sure that all of the resident's needs are being met. The coordinator will do both formal and informal monitoring of the resident's status, and will accommodate caregivers to the greatest extent possible; his/her job is to make sure care is delivered smoothly. It is often difficult for a coordinator to be aware of changes in an elder's cognitive status, and thus the informal referrals are particularly valuable.

The Subcommittee brainstormed ideas for future discussion and development of recommendations. Ideas that were raised included funding possibilities, expanded case management models, and increased communication between providers. Aspects of this discussion were also raised in the development of the MASP proposal.

## Other Council Activities

The funding for the Council also provides for other activities done under the aegis of the Council. The Council's staff person, Eliza Lake, serves as a liaison between Elder Affairs and Alzheimer's patients and their families, providers, and the interested public. She has served as an information resource for Massachusetts family members and providers, and for interested parties from outside the state. In fiscal year 2000, Ms. Lake attended the Alzheimer's Association's national conference on public policy in Washington, DC, where she was one of only a few state

employees devoted to ADRD issues. Other conferences she attended were the Boston Alzheimer's Symposium, a conference on Aging and Mental Retardation, and the Bristol, Norfolk, and Plymouth Partnership's conference on multicultural issues and dementia.

Ms. Lake attended and served as the staff person for all of the meetings of the Council and its subcommittees. She attended many other organizations' meetings in order to present the work of the Council, including a number of Alzheimer's Partnerships, which are regional coalitions of Alzheimer's providers and family members, other gatherings of providers, state agency groups, etc. These meetings included the Southeastern Alzheimer's Partnership, the North Worcester Alzheimer's Partnership, the Greater Milford Alzheimer's Alliance, the Greater Attleboro Area Alzheimer's Disease Collaborative, the Interagency and Intersecretariat Acquired Brain Injury Initiative, a meeting of the ASAPs' Executive Directors, a meeting of the Professional Counseling Center of New Bedford, and the annual meeting of the Bristol, Norfolk, and Plymouth Partnership.

Ms. Lake gave a training on the basics of Alzheimer's disease to a general staff meeting of the Executive Office of Elder Affairs, and presented workshops on dementia at the Western and Southeastern Massachusetts regional conferences of the Massachusetts Association of Councils on Aging. She was the keynote speaker at a conference on dementia in Springfield, where she spoke about the work of the Council. Ms. Lake also attended regular meetings of the Alzheimer's Association's Education and Advocacy Committees, the Multicultural Coalition on Aging, the Interagency and Intersecretariat Acquired Brain Injury Initiative, served as the contact at Elder Affairs for the Chronic Care Initiative focused on dementia, and prepared this annual report.

## **Future Activities**

The following are some of the activities for fiscal year 2001 outlined by the Council in June 2000.

- Invite all state agencies that presented to the Council in 1998 to return in the autumn of 2000 to update their report. This could be part of the recognition of the Council's reauthorization.
- If the state budget released from Legislature's Conference Committee in the summer of 2000 contains the nursing home quality initiative, the Subcommittee could recommend that the Council send a letter to the Governor asking that he not veto the elements of this initiative, which include a wage pass-through for certified nurse aides, a career ladder grant program for nurse aides, and education and job support for current and former welfare recipients in order to facilitate their becoming nurse aides.
- Recommend to the Executive Office of Elder Affairs that it designate home assessment and habilitation therapy training as purchased services for all ASAPs. At the same time, try to ensure that all ASAPs have information about the Home Modification Loan program.
- There has been a recent increase in the number of people who are being shuttled back and forth between nursing homes and geriatric psychiatry units in hospitals due to behaviors that are in fact typical of people with dementia. The Council decided that it would like to address this issue, at least in terms of increasing communication between the interested parties. The Council could call meetings of hospitals and

nursing facilities in conjunction with the Alzheimer's Association, and the Commonwealth's Long-Term Care Ombudsman Program.

- Investigate the training requirements for CNAs and homemakers in order to maintain the Subcommittee's focus on achieving a trained workforce.
- Invite the Department of Mental Health to talk to the Subcommittee about what it is currently doing for elders and those with dementia. This may be particularly interesting in light of the recent passage of the Mental Health Parity law.
- Invite the MA Commission for the Blind to come and talk with the Subcommittee about the issues facing the elderly who are blind and may be developing dementia, and about the assistive technology that exists to help this population.

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## Appendix A: Research Advances in 2000

### Top Alzheimer Research Advances of 2000 January, 2001

**Alzheimer's Disease and Related Disorders Association, Inc.**  
Washington, DC  
<http://www.alz.org/media/news/current/011900advances.htm>

Alzheimer research began only two decades ago when people with the disease and their families had very few options and no treatments were available.

But our understanding of Alzheimer's disease is growing rapidly, and the pace of discovery is accelerating. Because Alzheimer's is very complex, many lines of research are underway to unravel the mysteries of this devastating disease. Today, we are learning more about the underpinnings and causes of Alzheimer's and investigators are exploring many promising therapies for its prevention. Researchers are getting closer to conquering Alzheimer's, with breakthrough studies published almost weekly.

"The Alzheimer's Association will continue to be the driving force behind much of the promising research taking place," said Edward F. Truschke, President and CEO of the association. "Funds provided by the association help scientists gain a deeper understanding of Alzheimer's disease to ultimately find a prevention or cure."

In recognition of the achievements and developments in basic and clinical research that may have a significant impact on prevention and treatment of Alzheimer's disease from which four million Americans suffer, here are the top Alzheimer research advances of 2000:

#### Diagnosis

There is no single proven laboratory diagnostic test for Alzheimer's disease. Current clinical methods combine physical and neuropsychological testing with caregiver input and the physician's judgment. This method is about 90 percent accurate in diagnosing Alzheimer's disease.

One major group of experimental diagnostic studies is focusing on brain imaging techniques such as magnetic resonance imaging (MRI) and others are looking at positron emission tomography (PET) scanning to see if the early cognitive markers of Alzheimer's -- telltale changes in mental abilities and personality -- can be linked to early biological changes in the brain. These brain imaging and scanning techniques are getting closer to pinpointing brain abnormalities that might enable physicians to diagnose people with Alzheimer's disease before symptoms appear.

In the journal the Proceedings of the National Academy of Sciences, UCLA researchers published a study comparing PET scans that showed brain function of people at high risk for developing Alzheimer's disease with scans showing brain function of people who were not at high risk.

According to the researchers, initial PET scans showed that the group carrying the Alzheimer's disease gene APOE-4 had significantly lower function in specific areas of the brain located above and behind the temples. After a two-year follow-up, UCLA researchers found that the group carrying the APOE-4 gene demonstrated a five percent decline in function in the same two regions of the brain that appeared in their initial scans. According to the researchers, the group without the Alzheimer's disease gene showed decline only in an area located in the front of the brain which is consistent with normal aging.

### **Drugs -- Existing and in Development**

Despite years of frustration, researchers and doctors are now hopeful that they may be able to delay, and someday, prevent the onset of Alzheimer's disease.

This year, the U.S. Food and Drug Administration (FDA) approved a new drug treatment for Alzheimer's disease, rivastigmine (Exelon®). In addition to rivastigmine, there are two other drugs, donepezil (Aricept®) and tacrine (Cognex®), currently available to treat symptoms of Alzheimer's by improving cognitive function. Another drug, galantamine (Reminyl®) is under review by the FDA.

And many new drugs designed to either prevent or slow the progression of the disease, as many as 60, are in various stages of development.

Researchers also continue to investigate anti-inflammatory drugs to reduce the inflammation that accompanies plaque formation. Previous studies have indicated that ibuprofen and other nonsteroidal anti-inflammatory drugs (NSAIDS), including arthritis drugs called Cox-2 inhibitors, appear to reduce the risk of Alzheimer's.

In February, the National Institute on Aging (NIA) launched a clinical trial to determine whether treatment with certain NSAIDS will slow cognitive and clinical decline in people with Alzheimer's disease. The study will evaluate two NSAIDS: rofecoxib, a new cyclooxygenase (COX-2) inhibitor, and naproxen. This is the first clinical trial to test both classes of anti-inflammatory drugs prospectively in people with Alzheimer's disease.

The journal Neurology published a research study of the steroid prednisone, another anti-inflammatory drug. According to the researchers, a low-dose regimen of prednisone is not effective in the treatment of Alzheimer's disease. The researchers looked for changes over a one-year period in the cognitive performance and behavior of study participants as determined by a cognitive component of the Alzheimer's Disease Assessment Scale (ADAS) and other tests. According to the researchers, the testing showed that low-dose prednisone did not slow the rate of cognitive decline when those taking the drug were compared with those on placebo.

"It is encouraging to see that the NIA is conducting a study to determine whether certain NSAIDS will slow cognitive decline," said Bill Thies, Ph.D., Alzheimer's Association vice president of medical and scientific affairs. "More research like this is needed to clarify the role anti-inflammatory drugs may play in reducing the risk of Alzheimer's," he said.

In addition, scientists are investigating certain cholesterol-lowering medications. Two studies published this year have shown that there is a relationship between certain cholesterol-lowering medications (statins) and decreased occurrence of Alzheimer's disease.

In a study published in The Lancet, researchers at Boston University School of Medicine found that individuals who were prescribed certain cholesterol-lowering medications were about 70 percent less likely to have dementia compared to people who had no diagnosis of high cholesterol or exposure to other cholesterol-lowering medications. Individuals not treated with the cholesterol-lowering medications did not have a significantly reduced risk of dementia. A paper published in the Archives of Neurology researched similar conclusions.

“The Alzheimer’s Association is encouraged by the two studies showing a relationship between certain cholesterol-lowering medication (statins) and decreased occurrence of Alzheimer’s disease,” said Bill Thies, Ph.D., Alzheimer’s Association vice president of medical and scientific affairs. “Observational studies of this sort indicate a relationship but do not prove causation. The Association advocates that appropriate clinical trials using statins as a potential preventive for Alzheimer’s disease should be conducted,” he said.

### Enzymes

For more than a decade, Alzheimer researchers have been looking for enzymes that might be central to the formation of beta amyloid -- tiny protein fragments -- that accumulate into dense, insoluble plaques in the brains of people with Alzheimer’s. Scientists have hypothesized that these plaques cause cell death and lead to the decline in a person’s cognitive functions.

In February, the journal the Proceedings of the National Academy of Sciences published a study suggesting that researchers have identified a subset of the enzyme beta secretase —one enzyme believed to be involved in the formation of beta amyloid. By inhibiting the action of beta secretase, the researchers suggest that it may also be possible to inhibit the development of beta amyloid, preventing plaques from forming in the brain and thus preventing the progression of Alzheimer’s disease.

And, in June, researchers wrote in Nature that by inhibiting another enzyme believed to cause amyloid plaques, gamma secretase, it may also be possible to inhibit the development of amyloid plaques, consequently preventing the progression of Alzheimer’s.

“These findings represent a significant body of work and may be the foundation upon which the next generation of therapeutic drugs will be built,” said Thies. “But until clinical trials are conducted, we won’t know whether inhibiting these enzymes will affect the course of the disease,” he said.

### Nerve Growth Factor (Neurotrophic Factor)

The rapid pace of Alzheimer research over the past several years has opened many pathways that could lead to effective treatments for the disease. One general approach focuses on substances in the brain, including an essential chemical called nerve growth factor. How nerve growth factor works is not completely clear, but it is known to be one of several growth factors, or neurotrophic factors in the brain. While nerve cells in the brain do not divide in sufficient quantities to overcome Alzheimer’s disease, they can repair themselves after injury, and neurotrophic factors promote this regeneration.

Last year, researchers from the University of California, San Diego published a study in the Proceedings of the National Academy of Sciences on a gene therapy technique involving nerve growth factor, suggesting that they were able to revive or restore brain cells in aging monkeys to nearly their original state. The researchers took skins cells from older monkeys, inserted a gene

that makes human nerve growth factor, and then injected the modified cells into the brains of four monkeys. Once in the monkeys' brains, the modified cells began making nerve growth factor and appeared to revive brain cells.

In January, the researchers received approval from the Food and Drug Administration (FDA) to conduct Phase I clinical trials of the gene therapy experiment in humans. The researchers plan to enroll only eight people in this Phase I study. There are several requirements participants must meet to be considered for enrollment – one of these requirements is the ability to travel to San Diego, Calif., up to nine times in the first year of the study.

"The researchers describe a fascinating technique for producing nerve growth factor," said Thies. "By moving this research from animal trials to human trials, researchers have taken a step closer to determining whether this technique will have the ability to affect the course of Alzheimer's disease."

Meanwhile, human clinical trials are continuing on a number of nerve growth factor drugs.

### **Vaccine**

In 1999, scientists at Elan Corporation published a study in Nature on the immunization of mouse models with a form of the protein that begins the accumulation process of amyloid plaques in the brains of people with Alzheimer's disease. The researchers found that in transgenic mouse models -- mice genetically engineered to accumulate amyloid in their brains -- immunization with a synthetic protein fragment called AN-1792 significantly reduces existing plaques and prevents further plaques from developing.

The results from the study, if replicated in humans, would enable scientists to test amyloid reduction as a possible treatment strategy for Alzheimer's disease. Because the immune system of a mouse is very different from that of a human being, it is difficult for scientists to predict whether AN-1792 will be effective in humans.

In 2000, scientists at Elan began conducting Phase I safety trials on the compound of AN-1792 in other animals and initiated multi-dose Phase I clinical trials in humans. Initial results of the Phase I clinical trial, announced at World Alzheimer Congress 2000, showed that the potential vaccine was well tolerated in humans, according to scientists at Elan.

In total, about 100 individuals in the United States and the United Kingdom would be involved in the Phase I clinical trials of AN-1792. Individuals in the U.S. received a single dose of the vaccine through injection and, according to the researchers, no obvious safety concerns have been identified. Phase I multiple dose trials currently are underway in the United Kingdom.

"This is an exciting and encouraging study for the prevention and possible treatment of Alzheimer's disease," said Thies. "Announcements like this that are grounded in solid scientific research give us tremendous hope. We now are testing the amyloid hypothesis with this vaccine and traditional drug therapy, and we are moving closer to identifying an intervention that will be able to alter the course of the disease."

Researchers at Harvard Brigham and Women's Hospital also are investigating a potential vaccine. In the journal Annals of Neurology, the researchers write about their study of nasal

administration of a potential Alzheimer vaccine that they studied in transgenic mice —mice genetically engineered to develop Alzheimer's disease-like pathology.

According to the researchers, the brains of the mice treated with the nasal spray had significantly fewer Alzheimer disease-like plaques in the brain than the mice that were not immunized. Scientists are interested in testing the delivery of the peptide nasally because it may be better tolerated in people than repeated injections over the long-term. In this study, the strength of antibodies resulting from nasal administration of the vaccine was not as great as that from the injection approach, but it still was significantly effective against plaque formation.

### **Research Advances Announced at World Alzheimer Congress 2000**

The Alzheimer's Association (U.S.A.) assumed leadership of the world's largest international conference on Alzheimer's disease, World Alzheimer Congress 2000. Over a 10-day span in July, more than 5,000 world leaders in Alzheimer research and care united in Washington, D.C., marking the first time these Alzheimer specialists have come together for the vital purpose of sharing information on research and care to improve the lives of people affected by Alzheimer's disease. Here are some of the highlights of the research advances that were announced during the congress:

#### **Impaired Memory**

Danish scientists reported that failing memory may be a symptom of a treatable and reversible condition and not always a sign of Alzheimer's disease. Over a period of 40 months, researchers examined 785 individuals with memory problems. Only 43 percent were diagnosed with Alzheimer's disease or some other form of dementia. Six percent had selective amnesia and 11 percent were found to have some other cognitive deficit. Twenty- eight percent had no serious cognitive deficits and 12 percent were not classified.

In six percent of the people with Alzheimer's disease or some other form of dementia, the researchers found that a potentially reversible primary cause of the memory disorder existed. This does not mean, however, that Alzheimer's disease is reversible, the researchers explain. It does mean that some people with the illness may have an accompanying condition that contributes to or causes memory loss.

#### **Vegetables Rich in Anti-oxidants**

New findings reported at World Alzheimer Congress 2000 suggest that eating high amounts of vegetables rich in vitamin E and vitamin C is associated with lower risks of dementia and Alzheimer's disease.

Researchers collected the dietary habits of 5,395 men and women aged 55 and older who were free of dementia. People who participated in the study completed questionnaires about dietary habits and were interviewed by dietitians. The researchers found that on average, people who remained free from either form of dementia had consumed higher amounts of beta-carotene, vitamin C, vitamin E, and vegetables than the people in the study who developed Alzheimer's disease.

#### **Therapy for Moderately Severe Alzheimer's**

Researchers reported findings suggesting that memantine, a drug that acts on a key central nervous system receptor, may help slow the progression of moderately severe to severe

Alzheimer's disease. The researchers found in their study of memantine that after six months, both the placebo group and the treatment group declined. However, after several assessments to evaluate cognitive function, activities of daily living and behavioral change, the researchers found that the treatment group performed significantly better than the placebo group in cognition and daily activities, without changing behavioral symptoms.

### **High-Fat Diet**

According to research presented at World Alzheimer Congress 2000, a high-fat diet during early and mid-adulthood may be associated with an increased risk of developing Alzheimer's, especially in people with a marker called the ApoE-e4 allele. In a retrospective analysis that examined foods eaten by 304 men and women (72 with Alzheimer's disease and 232 healthy individuals), researchers found that people with the ApoE-e4 allele who also consumed the highest fat diets had a seven-fold higher risk of developing Alzheimer's than people with the marker who ate lower fat diets.

"It has long been hypothesized that early life experiences may affect the development of Alzheimer's disease," said Thies. "Proper nutrition and a healthy diet are essential for maintaining overall good health and can be beneficial to both people with Alzheimer's and caregivers."

## Appendix B: ABI Initiative Fact Sheet



Commonwealth of  
Massachusetts

# Acquired Brain Injury Interagency and Intersecretariat Initiative

## ***Mission Statement***

The Acquired Brain Injury Interagency and Intersecretariat Steering Committee recommends the development of interagency and intersecretariat mechanisms that improve and enhance access to comprehensive and coordinated services for people with ABI who are currently not being served or not being served effectively.

## ***Participating Agencies and Secretariats***

### Executive Office of Health & Human Services

Department of Mental Health  
Department of Mental Retardation  
Department of Public Health  
Department of Social Services  
Department of Youth Services  
Division of Medical Assistance  
Mass. Commission for the Blind  
Mass. Commission for the Deaf  
and Hard of Hearing  
Mass. Rehabilitation Commission

### Executive Office of Elder Affairs

### Department of Education

## ***Goals and Work Plan***

The Steering Committee and Subcommittees that make up this initiative have been at work since September 1997 to improve the service delivery system for those with Acquired Brain Injury in Massachusetts.

The goals and work plan are as follows:

- *Develop a mechanism to better identify the ABI population within state agencies*
- *Identify the needs of the ABI population*
- *Evaluate the capacity of the system to provide services to people with ABI and identify changes to provide these services*
- *Develop an interagency service model*
- *Educate our agencies, ourselves and the community-at-large about those with ABI, their needs and appropriate services and treatment*
- *Maximize resources to better serve those living with ABI*
- *Improve collaboration among secretariats, state agencies, consumer advocates and the private sector to improve services*

***For more information about this Initiative, please call:***

Debra Kamen, Co-Chair  
Director, MRC/SHIP  
(617) 204-3852

Betty Anne Ritcey, Co-Chair  
Director of Client Services, EOHHS  
(617) 727-7600

Michael Banville, Coordinator  
Program Coordinator, SHIP  
(617) 204-3852

## Appendix C: Nursing Survey



### Governor's Advisory Council on Alzheimer's Disease Survey of Massachusetts' Nursing Programs

The Governor's Advisory Council on Alzheimer's Disease and Related Disorders is an independent group of providers, advocates, professionals, family members and legislators charged with improving the provision of care and services for people with Alzheimer's disease and related disorders (ADRD) and their families. Toward this end, the Council, in collaboration with the Board of Registration in Nursing, the Mass. Association of Colleges of Nursing, the MA/RI League of Nursing, and the Alzheimer's Association, is collecting information about the education of those professionals who may care for those with ADRD, with a focus on nursing.

The following questions are intended to give the Council information about the current state of nursing education in the state, and to point us in the direction of future policy recommendations. Any information you can share with us will be extremely valuable in the process of improving the lives of people with ADRD and their caregivers. Thank you.

**Name of Program/Institution:** \_\_\_\_\_

**Type of Program:** (check all that apply  
and include number enrolled)

**Number Enrolled:** \_\_\_\_\_

LPN  \_\_\_\_\_

**Number of:**  
Full-time faculty \_\_\_\_\_  
Part-time faculty \_\_\_\_\_  
Faculty prepared in  
Gerontology \_\_\_\_\_  
Total Program  
Hours for degree \_\_\_\_\_  
Total Program Hours  
available in  
Gerontology \_\_\_\_\_

RN/Diploma  \_\_\_\_\_

RN/ADN  \_\_\_\_\_

RN/BSN  \_\_\_\_\_

RN/RN to BSN  \_\_\_\_\_

RN/MSN  \_\_\_\_\_

Post-Masters Certification  \_\_\_\_\_

Ph.D./DNSC  \_\_\_\_\_

**PLEASE RETURN THE COMPLETED SURVEY TO THE BOARD OF  
REGISTRATION WITH YOUR ANNUAL REPORT.**

**Please answer the following questions. If you need more room for your answers,  
you can attach an additional sheet of paper.**

**Does your program offer any courses devoted to geriatric nursing?  yes  no**

If yes, please list title(s), number of hours, and course description:

**Do you offer any courses that contain some integrated content on geriatric nursing?**

yes  no

If yes, please list course title(s), number of hours devoted to geriatrics, and what topics are related to elder care:

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**Do you offer any courses that are devoted to dementia care?**

yes  no

If yes, please list course title(s), number of hours, and course description:

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**Do you offer any courses that contain some integrated content on dementia care?**

yes  no

If yes, please list title(s), number of hours devoted to dementia care, and course description:

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**Do you offer any clinical practice or internship/externship experience that is used to support geriatrics?**  yes  no

If yes, please list clinical agency(ies), the type of facility, and the type of experience:

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**Do you see the need for a specialization in geriatric and/or dementia care nursing?**

yes  no

**Comments:** \_\_\_\_\_

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